



Transcript of Interview with Susan Bithrey

David: Welcome to our Dementia Dialogue podcast where we are discussing changing and adapting when dementia enters a person's life. Dementia Dialogue thanks our sponsoring partner the Center for Education and Research on Aging & Health, Lakehead University, Thunder Bay, Ontario.

Our guest today is Susan Bithrey who accompanied her husband Reg who lived with dementia for a period of eleven years. In talking with Susan, I was struck by her ability to reframe experiences in her life as Reg's condition progressed so that mistakes that she felt she made became lessons learned and strengths found where many of us might see weakness.

Susan reading: Journal Entry September 8 2006. For many months now, I've been wondering when will I see the day that I have to start writing things down. Today seems like the day. Something terrible is happening to Reg's memory and I can't pretend any longer to myself. The fog or whatever was creeping stealthily into our lives and I guess I've been playing a bit of the game so far. You know, if I don't talk about it or actually write it down, maybe it's not really there.

Today it was an order of lumber. He's building a shed for the backyard, a small construction job in the order of things- a task he would have handled easily with one hand tied behind his back in the past. But he seemed so overwhelmed and confused by small details. Today he ordered wrong lumber. Oh he says that the woman at the counter made a mistake. But I know, I just know that he's given them the wrong information either by getting flummoxed at the desk or losing his train of thought. "I just can't seem to multitask", he said wearily today as we unsnarled the confusion between what we actually needed and what had arrived on the truck. Small things but they begin to add up. I begin to see a scary future soon.

Who can say how to document this? Perhaps if I'd been writing things down for the past year or so I might be able to look back and detect a pattern. But that's the thing about problems like this. By the time you figured out that there really may be a problem you're

really far into. You can't really plot how you got there or where you made the first or second or third moves that actually got you into this mess. It's hard to even know what to write down now. After all, what am I trying to achieve? A journal for others to read later in a diary; to help me focus my own thoughts; a written record to compare every few months and determine whether things are declining, improving or staying the same. All of the above. Part of me hopes that I'll start writing and then a few days into the exercise I'll tell myself that I'm all in a flap over nothing. Right now I'm worried enough to feel the need to get this record under way and allow a dark elephant to finally be acknowledged until tomorrow then.

David: What you've just heard is the first entry in a journal kept by Susan Bithrey when she first sensed the seriousness of her husband's changing condition. Susan has joined me today from Thunder Bay. Welcome to Dementia Dialogue, Susan.

Susan: Thank you.

David: Thank you for joining us. Susan, I'm wondering whether you might be able to describe to me some of the other symptoms that were of concern to you as background to this sentinel event in the lumberyard that caused you to elevate your level of concern.

Susan: Well in addition to this sort of cataclysm that occurred around the garden shed, Reg had over the past year began to be kind of fascinated with or worried by the calendar. He was constantly checking- unsure of what day it was and his memory was not what it used to be. And I think those were kind of the main things. It worried me- that he fixated on the calendar and came out almost obsessive compulsive.

David: Yes okay so it was as much of a behavioral manifestation as well as cognitive.

Susan: Yes.

David: After this particular incident, what were some of the next steps that, you know, that led toward Reg becoming diagnosed with early onset dementia? I think he was 61 at the time that he was diagnosed, if I recall

Susan: Going on 62. And his official diagnosis was made a year after the Journal. But the doctor was kind enough to set up an appointment with the neurology department at Sunnybrook Hospital in Toronto which was about a three hour drive from where we were living and that took a full year to be arranged and at the very first interview with us which took the best part of the day it was clear that what we had going on was Alzheimer's.

David: Can you describe a little bit of your feelings or reaction when you received the diagnosis. It was clear at the end of that one day that something serious had set in on Reg.

Susan: Well I think as with most people, once you actually hear a diagnosis spoken out loud, there's a sense of relief that you're not crazy. Yes. However, it was you know- there was a lot of sorrow and anger that this should be happening to us. We were, you know, a kind of golden retiree, younger senior couple that thought we were bulletproof. I guess we weren't. Yes there was the realization that we were as vulnerable as anyone else.

David: Yes. You mentioned that you have sons that sensed some problems with their father. What was their reaction when you shared the diagnosis with them?

Susan: There was profound sadness on their part. And of course worry, because you have to wonder is this a one off. This is just something cosmic that's landed on our father and it won't touch anyone else or is this going to continue on? But there was overwhelming love that they were going to support whatever decisions we made around how the two of us were going to live with this. And Reg had made the decision almost immediately that we would no longer live in Southern Ontario. He wanted to return to home, to Thunder Bay and so we shared that with the boys and they assured us that they would help us every step of the way.

David: Yes and when you returned home did enjoy the support you anticipated in making that decision.

Susan: Yes. And then some. He has extended family here. And they were right there for us. We have an army of friends and we were put in touch with professional organizations that were going to be needed. We didn't jump right in with those right away but in the meantime we were able to settle in.

David: I think you touched upon a really crucial issue around decision-making and balance in a spousal situation when one person develops a cognitive impairment. And you know there may be a tendency' it may have been, you know, for the other spouse to perhaps assume a little bit more control than might be appropriate or authority. I wonder if you could just if we could explore that for a moment.

Susan: Well I think it happens a lot. Not just with the spouse or the immediate caregivers but people everywhere it seems around someone who is diagnosed with Alzheimer's, can jump to conclusions and say that life is kind of over for them and we need to help and we need to take over. People stop asking them for their opinions about things assuming that they can't take things through and that they can't speak for themselves. I've learned with my husband that he had still lots to say and I had to start kind of opening my ears and I have since his passing and through the work that I was doing, I know now, that they were becoming their own advocates and speaking for themselves. And yeah I I made that mistake. You just kind of started rolling up my sleeves just a wee bit too soon and had to kind of pull back. I got some advice from my younger son that I took to heart. He said to me "Mom you have to let go of always needing to correct dad when he says something that's wrong and stop getting angry when he says something hurtful. He doesn't mean it." And I would hear his voice in my head.

David: Those are very wise words that your son gave to you. I wanted to explore with you a little bit. I was taken with the use of the journal at such an early stage in your journey in Reg's journey with dementia and I wondered whether you could talk a little

bit about yourself before the condition. How is it that journaling became a part of your strategy for working with this condition?

Susan: Well I sort of dragged myself to tears and screaming into it. People have always told me that I write well but I never really followed up on that. And when I retired, I was given a journal with the hope that I would fill it in and talk about my adventures. And it sat empty. That was the journal that I picked up the day that I decided that I was going to write this all down. Once you get going as a journalist you realize that it's helping. It creates a little space in the day where you can kind of gather your thoughts. It can be as simple as just recording kind of the medical stuff that has to go on around your loved one's illness. I guess something that people had always expected me to do. I had tried to not follow through. And this time I thought this is huge. Then the journal ended up being five volumes, one for each year. They're not massive but they do document what our journey looked like.

David: So they were both a tool for documentation as we mentioned but also a tool for kind of reflective learning, if you will, that you can write something down and then look at it and try to understand it a little bit more deeply.

I'm wondering Susan, you mentioned you know, the first few years in Thunder Bay were relatively normal. And while people suggested you might join clubs or organizations, I wonder if you might kind of describe that eventual outreach to some of those resources.

Susan: The first outreach for me was as a result of a chance encounter with someone I had known when I've lived here before and when she found out what we were going through, she suggested that I meet with a spiritual adviser/grief counselor. And I said to her, "Well why would I need a grief counselor? No one has died." And she said, "Susan something has died. And I think you would benefit from meeting Catherine and hearing what she has to say that might be helpful. There's a lot that's going to come up for you." That was the first thing I did and we had about a two year professional relationship in which I was just able to have a space where I could go and I kind of howl at the moon if I needed to. And there was no judgment. I could tell her anything and that was such a help. Sometimes you have things to say that aren't very nice because there's a lot of anger and grief about losing things that you had expected to be able to hang on to for a

lot longer than you did. And it was wonderful to have someone whose job it was to simply listen.

David: Yes. Yes. You had mentioned earlier that you and your husband were seen by many to be kind of model retirees.

Susan: Yes.

David: That sense of loss of what you anticipated to be your future would have been quite profound.

Susan: And when he was diagnosed, within about a year of this diagnosis, he had to give up his driver's license and in my view was more painful than the day that he learned that he had Alzheimer's.

David: The loss of a driver's license is definitely one of the most catastrophic things that happens to a person in the early stages of dementia. There's such a social and cultural value assigned to a driver's license as we're growing up.

Susan: Yes but it was clear that he had cognitive deficiencies that were eventually going to cause him to lose the license and in the end, I felt that maybe it came a little early but it came at a time when I was still able to reason with him about what was happening. And he accepted it and I became the principal driver and ironically I did not learn to drive until I was 40.

So he always considered me a new kid.

And we began it with a few fights when I was be the driver and he would try to correct me and I would get angry about it. And finally I came to the realization and that he'd been driving longer than I, that he was a really skilled driver and maybe it would be in my best interest to listen to what he had to say. So I just began to say things like "Well if I'm doing it wrong, what should I be doing?" And he would tell me. I think to this day I'm a much better driver for that period in our relationship where he became the coach and it gave him a real sense of still having something to offer which was lovely.

David: So yeah that's really that's a very interesting way of kind of adapting to a new situation where he has lost his license perhaps a bit prematurely, because of that sense of anxiety and agitation maybe that the computer part of the test -you and he were able to craft a new contribution for him to make through other kind of coaching as you said.

Susan: Yes. Yeah. I don't want to make myself out of any kind. I didn't come to it quickly once. No but once I did it was really a game changer.

David: I think, you know, there are lessons to be learned in all of these events that occur in a person's life and of course that's the reason why we're doing Dementia Dialogue is to have people describe some of these stories and some of the lessons learned.

So there is an interval of roughly eleven years where he was living with dementia and the first half of those years were relatively normal if you will, normal situation where you were able to live in the community and live relatively satisfactory lives.

Susan: Yes yes.

David: And then circumstances changed a little bit. I wonder if you might describe but what were some of those changing circumstances.

Susan: When Reg was diagnosed, he was told that in addition to Alzheimer's, he was exhibiting signs of aphasia which means that he was parts of his brain that controls speech and communication were beginning to be interfered with and that that was only going to get worse. He lost words rather rapidly and he didn't understand words that were being spoken to him. So conversations, you know, kind of changed radically. His inability to speak eventually caused him or was connected, I think, with his exhibiting behaviors.

He became sort of aggressive. He couldn't make you understand what he wanted or didn't want by speaking to you about it. So he would show you. If he didn't want something or he didn't like something, he would take me by the wrists and make it understood that no this wasn't this wasn't a good idea. He began to be restless. He

began to be suspicious of the few hours of respite care. He didn't like the people to come into the house. He didn't understand why they were here. He further didn't understand why I wasn't [there] and all of these things kind of escalated.

He began to run away from home. He became fascinated with the river here by our house and it used to scare me because early in his disease, he would threaten to end his life and I would say, "Well how would you do that?" "I would find a place where there's lots of water." So just everything became kind of overwhelming and his behaviors in the end overwhelmed him. And we had to, I had to call a crisis response team, here in the city. And when they arrived, he made a threatening overture to me and they decided that it wasn't up to me to say whether he was going to be taken into hospital. It was their decision that he had to go to an emergency and ultimately to the mental health unit which was the only place at the time of the city that there was to go for his own protection. And so this very gentle sweet man, at this point, was considered dangerous and that was heartbreaking.

David: Yes. Yes it must been. Now so he was admitted in to a mental health unit at the hospital.

Susan: Yes. He was there for 11 weeks and it was not a pretty story. That was one of the most difficult times in his in his whole disease. I had to be his personal support worker basically because he wouldn't allow anyone on the hospital staff to do things for him. So I was there for eight nine hours a day and and finally he would fall asleep exhausted and I [would] go home. Finally at the end of a long period of time, a local psychiatrist here who was just fed up to the teeth with the system, decided that she was going to put him into a dementia care program here that was officially closed but she made an exception.

David: I think that must be one of the most difficult periods for not only the person with the condition- the level of confusion and anxiety and misinterpretation that people are so vulnerable to but also on the part of the family where they, as you said this dear gentle man is being observed in ways that are just so contrary to his nature.

I'm wondering Susan during this period of time, were you involved with the Alzheimer Society, for example or other organizations?

Susan: Yes. The Alzheimer's Society, they were amazing. I went through all their helpful courses and programs to kind of hone some of the skills that I knew I was going to need. And they were amazing and I became a bit of a spokesperson for them, did some did some public speaking sharing the journey that Reg and I were going through. And I also became involved with the Center at Lakehead University.

David: Now I'm interested when you were, when you would be speaking to groups. I'm expecting that you would have come in contact with people that were perhaps experiencing dementia in their lives, either themselves or in a relationship with another person, who may not have reached out or publicly kind of identified dementia. Did you encounter folks like that?

Susan: All the time. Yes. And you know they would thank me for kind of going public with what was happening and say that I had kind of touched on some things that were going on in their lives, maybe give them some direction or I would just get phone calls from people who knew people who said you know suggested that if I called you some suggestions to make.

David: I appreciate your continued commitment to your working in this area related to dementia your volunteer work at the care home. And I think you're as involved as a volunteer from time to time with the Center at the university.

Susan: Yes, help edit a newsletter for caregivers.

David: I'm wondering if you might describe other parts of your life or kind of using the phrase 'you're moving on'. My sense is that you are honouring your experience but at the same time moving on. I wonder if you might discuss that for a moment, after Reg passed away.

Susan: I stayed on all of the committees that I had been on and I've continued to kind of go forward trying to do the work and at a certain point I had to uncouple from almost everything. And that's when I started to allow myself to grieve and to rest. I simply had not realized how tired I was. I was exhausted and I think all through the caregiving and for a long time afterwards, many caregivers just do that. I'm fine. Just carry on. Let's just keep doing this. And then something happens and you just kind of hit a wall and realize "I can't do this anymore." And after Reg passed away self-care became very important.

David: Susan we're coming to the end of the interview. Now I'm wondering whether you have any last moment thoughts, any lessons learned that you would like to share with our listeners before we come to a conclusion.

Susan: This was a journey that I was absolutely unprepared for, in every way. As most caregivers do or as lots of caregivers do, I learned on the job. In trying to be proud of what I did, I always try to remember that I was only required to learn how to be a caregiver. My husband had to go through disease. He got the worse end of all of this. I only hope that I was able to make some things along easy for him. I hope I really hope.

David: Thanks Susan.

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Thanks to our sponsor for today's episode the Center for Education and Research on Aging and Health at Lakehead University Thunder Bay Ontario. Please join us for our next podcast on Dementia Dialogue as we continue our conversation on changing and adapting as part of the dementia journey. My name is David Harvey.

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